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Physical & Occupational Therapy in Pediatrics

Original research

## What makes participation meaningful? Using photo-elicitation to interview children with disabilities

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### Declaration of interest statement

The authors have no declaration of interest to report.

**ABSTRACT**

**Aims:** The purpose of this study was to describe meaningful participation in everyday life from the perspectives of children with disabilities. **Methods:** Nine children (5–10 years, mean age 7.2 years, 5 boys, 4 girls) with disabilities participated in individual photo-elicitation interviews. The interview data was transcribed verbatim and analyzed with inductive content analysis. **Results:** The children's meaningful participation mainly comprised free leisure activities that fostered enjoyment, capability, autonomy and social involvement with family and friends. The children's emotions and physical sensations, opportunities to influence, knowledge about the activity and the participation context, presumptions and previous experiences of the activity and the environment played a vital role in their decisions to participate. **Conclusion:** The meaningful participation facilitated enjoyment and self-determination for the children. Identifying personal and environmental factors supporting or restricting participation from the child's perspective emerges as important in order to provide opportunities for the child's meaningful participation in everyday life. The photo-elicitation interviews demonstrated the potential to act as a tool to identify and explore the children's views about participation in a real-life context.

**KEYWORDS:** children's rehabilitation, activities, participation, photo-elicitation interviews

The International Classification of Functioning, Health and Disabilities for Children and Youth (ICF-CY) defines participation as involvement in life situations (WHO, 2007), including a wide range of community and family activities for children. Imms et al. (2016) suggest that attending activities and getting involved in them should be understood as two essential elements in participation.

A child's wellbeing and development (WHO, 2007) and quality of life (Dahan-Oliel et al., 2012) are positively affected by the child's opportunities to participate in life situations. Studies have shown that children with disabilities are at risk of limited participation in everyday life (Axelsson et al., 2013; Bedell et al., 2013). Thus, participation is emphasized as an integral part of pediatric rehabilitation (Palisano et al., 2012; Shikako-Thomas et al., 2014). The main focus of the rehabilitation, however, has been on impairments to the child's body functions and structures, and restrictions on task-oriented activities – not on participation (Anaby et al., 2017; Jeglinsky et al., 2014).

Environmental factors (Anaby et al., 2014; Colver et al., 2012; Imms, 2008; Law et al., 2004), age and physical functioning (Law et al., 2004; Orlin et al., 2010), gender (Law et al., 2004) and pain have a major influence on the child's participation (Fauconnier et al., 2009). Further, significant predictors for participation intensity in leisure and recreational activities are the children's own preferences (King et al., 2006). Hence, in order to enhance the child's participation, it is vital to understand what is important and which factors limit and support participation from the child's perspective. This is also highlighted because several studies have reported that the child's own views may differ from those of their parents (Maggs et al., 2011; Rosenberg & Bart, 2016; Schiariti et al., 2014).

According to the United Nations Convention on the Rights of the Child (CRC), children are entitled to influence matters that concern them consistent with their age and maturity (United Nations, 1989). In this study, the child is understood as a social actor and agent, influencing their own functioning and life course (Bandura, 2001), and whose interaction with others makes a difference (Mayall, 2002, p. 21). Optimally, participation provides children with opportunities to engage with their world in a meaningful way (Palisano et al., 2012), and endorses children as agents in their own lives (Kellet, 2009). Jyrkämä (2007) scrutinizes agency in daily life as the interaction between a person's abilities, opportunities, musts, wants, feelings, and competences, which change and adjust to different situations and environments. In this study, these modalities of agency were used as a

framework to concretize the realization of the child's agency in meaningful participation. The purpose of the study was to describe meaningful participation in everyday life from the perspectives of children with disabilities in order to strengthen their agency. To this end, the research questions were: 1) Which types of participation are meaningful for children with disabilities?; 2) What do children consider meaningful in participation?; 3) Which factors limit or support children's participation?

## **METHODS**

### **Design**

The study applied a qualitative research design. The data collection was arranged to be child-friendly and ethically sound. The study was approved by the Ethics Committee of the Universities of Applied Sciences in the Helsinki Metropolitan area. The study utilized photo-elicitation interviewing (Einarsdottir, 2005; McCloy et al., 2016) and creative methods such as drawing and imaginative play, which have proved to be useful when researching children's perspectives (Cameron, 2005). Photo-elicitation interviewing was chosen to capture the children's perspectives because: 1) it is easy and enjoyable for children and parents to accomplish, 2) taking photographs promotes a child's active involvement in the research process without limiting the participation of children whose functioning is more severely limited (as might be the case with drawing, for example), and 3) the photographs concretize the participation in the child's daily life.

The study participants were recruited through three pediatric rehabilitation centers in Southern Finland. Both parent and child were asked for their voluntary consent to participate in the study by their therapists, who gave the parents written and oral information about the study. Additionally, a written and pictorial description of the study that the parent could read out loud or the child could read herself was provided (Barker & Weller, 2003). After approval, contact with the researcher was established.

We collected the data in two phases. First, we asked the parent to take one or more photographs together with the child regarding activities and participation in the child's daily life that the child considered important, or wanted to do or learn. The participants used their own cameras to take the pictures. Further, we requested the parents to ask and write down what the child wanted to convey with the photograph. The parents then sent the short descriptions and the photographs that

the children had selected to the researcher. In the interview situation the children had the opportunity to decide if a) they want to withdraw some photos from the data, or b) they had changed their mind about the importance of the photographed activity, and/ or c) did not want to tell about certain photo. Secondly, we agreed upon a location and a time according to the family's wishes for the children's individual and functional interviews based on the photographs.

## Participants

Nine children (5–10 years, mean age 7.2 years, 5 boys, 4 girls) with physical (N=6) and developmental (N=3) disabilities participated in the study (see Table 1). The main diagnoses of the children were cerebral palsy (N=4), autistic disorder (N=2), hemiplegia and visual impairment (N=1), specific developmental disorder of motor function (N=1) and developmental disorder (N=1). The inclusion criteria were: a) the child was undergoing rehabilitation funded by the Social Insurance Institution of Finland (Kela), and b) the children could express themselves verbally or make themselves understood with alternative communication methods. Kela provides rehabilitation for children whose functioning is limited in their daily life (Kela 2017).

**Table 1.** Characteristics of participants (N=9, F=female, M=male) and interview situation

Age	Sex	Main type of disability/ impairment	Communication	Interview location/ situation	Activities during interview
5	F	Physical/motor	Speech	Home	Drawing, showing favorite activities and toys
5	F	Developmental/ behavioral	Speech	Home, Mom present	Drawing, play
5	M	Physical/motor	Speech	Metropolia UAS	Imaginative play, singing
7	F	Developmental/ behavioral	Speech and pictures	Home, Mom supported	Showing favorite toys and own things
7	M	Physical/motor	Speech	Home	Imaginative play, showing favorite toys and games
8	F	Physical/motor	Speech	Home	Drawing, showing favorite things
9	M	Developmental/ behavioral	Speech, pictures, sign language	Home, Mom supported	Playing with cars, showing favorite activities and skills
9	M	Physical/motor	Speech	Home	Drawing
10	M	Physical/motor	Speech	Home	Showing actions related to favorite activity

The children and parents decided together whether the child would be alone during the interview. Two of the children used pictures and/or sign language with speech, and their mothers were present during the interview to help interpret what the child was saying. Care was taken to ensure that the children felt comfortable and that a trusting relationship was created. This was initiated by the child choosing the location and the activities during the interview (Table 1).

## Procedure

The interview themes were formulated to cover the six modalities of agency (Jyrkämä, 2007) and to provide insights into different aspects of the child's meaningful participation (see Table 2). Questions were modified to help the children understand. Follow-up questions were designed to help the child elaborate. The children's photographs helped them to remember and talk openly about the participation. Additionally, the children had an opportunity to talk about other important participation types that they had not photographed. The interviews were conducted by NV.

**Table 2.** Examples of the interview questions

Study question	Interview theme	Interview question
1	The participation types in the photographs	Can you tell me what this photograph is about? What is happening in this photograph?
2	Child's <i>wants</i> , important things and aspirations	What is important to you in this activity and participation? What do you like about this participation?
2	Child's <i>feelings</i> , experiences	How do you feel when you participate in this activity? Can you tell me more about what you are doing in this activity?
2, 3	Child's <i>abilities</i> , <i>competences</i> , difficulties or barriers	What are you doing well in this activity? Is there something that is difficult or that you don't like?
2, 3	Child's <i>possibilities</i> , <i>musts</i>	What enables you to participate? What is needed for the participation to succeed? Is there something that is compulsory?
2, 3	Context of the activity, environment	Do you like to do this activity alone or with someone else? Who? Where does the activity and participation take place?
3	Other? Supporting and limiting factors	What helps you to participate in the activity? Is there something that makes it difficult for you to participate?
1, 2	Other type of participation	Is there anything else you want to tell me that is important to you or that you wish to do/learn?

<sup>1</sup> What are the types of participation that are meaningful for children with disabilities?

<sup>2</sup> What do children consider meaningful in participation?

<sup>3</sup> What factors limit or support children's participation?

We received 31 photographs describing 22 different participation types in the children's lives. Four children sent two photographs describing the same participation type twice, and these photographs

were included in the data as one type. One photograph depicting an activity of daily living (ADL) was excluded from the data because the child decided during the interview that it was not important for him. During the interviews, the children expressed eight new participation types that they had not photographed. The audio-recorded interviews lasted 22–53 minutes (mean time 38.4 min) and were transcribed verbatim by a research assistant (89 pages in total: Times New Roman, font size 12 and line spacing 1).

### **Data analysis**

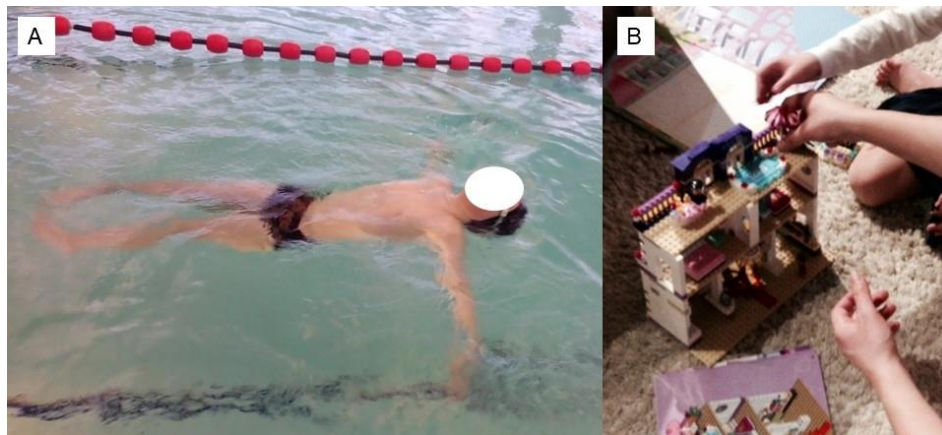
In order to answer the first research question, the different participation types in the children's photographs and the interviews were collected and grouped under similar forms of participation. These groups were named according to the nature of the participation. To address research questions 2 and 3, the interview data was analyzed by means of inductive content analysis (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004). The process involved reading the children's interviews to gain an overall impression, and identifying meaning units consisting of words, phrases or sentences related to each other through their content. The meaning units were further shortened while retaining the same meaning (condensed), coded and grouped into subcategories and categories according to similarities and differences through abstraction. All in all, 13 general categories and subcategories describing the manifest content of the interview data were identified. Finally, four main categories emerging as latent data content but still close to the original text were formulated. The interview data, codes and categories were compared throughout the process to reinforce trustworthiness. The analysis was conducted by NV and reflectively discussed with SS and LH.

## **RESULTS**

### **Types of meaningful participation**

The participation types described by the children (see picture examples in Figure 1) included: sports and physical activities, creative play and activities, tasks and responsibilities and other informal leisure activities (Table 3). All of the children described play involving the use of imagination as a meaningful activity. The participation types were mostly free recreational activities that the children engaged in with family members or friends, but the tasks and responsibilities were more formal actions that the children wanted to manage independently or were responsible for.





**Figure 1.** Picture examples: A) Boy swimming and B) Girl building a Lego house with her father.

**Table 3.** Type of participation and number of children who described it (N)

Doing sports and physical activities	– Climbing and swinging in a playground (4)	– Parkour (1)
	– Swimming and playing in the water (3)	– Skateboarding (1)
	– Cycling (2)	– Trampolining (1)
	– Horseback riding (2)	– Wheelchair basketball (1)
	– Running, playing tag (2)	– Sliding down a slope (1)
	– Football (1)	– Ice hockey (1)
Creative play and activities	– Imaginative activities with different kinds of toys or games (9)	– Singing and acting (1)
	– Drawing and coloring (3)	– Playing a musical instrument (1)
	– Building robots, Lego objects, and castles (2)	– Playing/using an electronic device (2)
Tasks and responsibilities	– Going to school independently (1)	– Doing homework (1)
	– Learning to walk without falling at the family's cabin (1)	– Climbing stairs (1)
	– Doing stretches (1)	– Watering own plant (1)
Other informal leisure activities	– Eating (3)	– Hanging out and fooling around with family members or friends (2)
	– Baking/cooking with parents or friends (2)	– Watching TV or videos (1)
	– Visiting interesting/memorable places with family members or friends (2)	– Reading (1)

### What is meaningful participation?

According to the results, the main elements of meaningful participation are: enjoyment, capability, social involvement and autonomy. A diagram of the elements depicting meaningful participation from the children's perspective is shown in Figure 2.





### **Limiting and supporting factors for participation**

The children described factors that either supported or limited their participation (Figure 3) and these factors were often the opposite of each other. The children expressed physical and emotional feelings related to the participation context such as cold, or fear of falling or hurting themselves, which restricted their participation. The children considered their participation in light of previous experiences and presumptions. This sometimes resulted in a decision not to take part, especially if the child felt insecure, encountered difficulties with the tasks, or if the earlier participation experience was negative. Water enabled activities such as hopping or doing somersaults, which were difficult or frightening to do otherwise. Fear of being laughed at or bullied restricted children's desire to take part. Knowing and remembering the rules and expectations of how to act in different games, and environments helped the children to feel confident and supported participation.

R: Is there something that makes it harder for you to participate in that (game) with others?

C: That I don't have that much knowledge. It's not nice when someone is playing games that you don't know. And it's a bummer when someone doesn't explain the rules to you. (Boy, 7 years)

**Figure 3.** Limiting and supporting factors for participation

## DISCUSSION

The children's meaningful participation types in this study were mainly informal recreational activities that facilitated enjoyment, social involvement, autonomy and capability for the child. The children expressed curiosity to learn and develop their abilities. They wanted to be active agents in making choices, and to negotiate adaptations and solutions enabling them to participate in the preferred activity. The results showed that the children's emotions and physical feelings, opportunities to influence, knowledge about the activity and the participation context, presumptions and previous experiences have an effect on decisions to take part. By acknowledging children as agents and exploring the children's meaningful participation through the modalities of agency in this study, it was possible to see how children influence and consider their participation in a real-life context.

In line with previous studies (Coster & Khetani, 2008; Willis et al., 2017), the children's perspectives in this study demonstrated the importance of the social aspects of participation. Children prioritized leisure activities and playing with other children or family members as a key activity in their everyday lives. The meaning of friendship, sense of belonging and acceptance in a group (Morrison & Burgman, 2009; Willis et al., 2017), play (Chiarello et al., 2014) and leisure activities with peers (Shikako-Thomas et al., 2014; Vroland-Norstrand et al., 2016) are well recognized. In rehabilitation, however, social involvement with peers and friends are rarely established as goals (Anaby et al., 2017) and ADL activities aimed at increasing the child's independence are often more valued by parents (Vroland-Norstrand et al., 2016).

Enjoyment, as a key element in the children's meaningful participation in this study, has been included in some participation assessment tools (for example CAPE and PAC) as a subjective dimension and as a preference in many models for participation (Khetani et al., 2015; King et al., 2006; Palisano et al., 2012). Rosenberg and Bart (2016) state that a child's personal factors such as gender, age and emotional functioning have an effect on their enjoyment. In this study, the children's positive emotions and physical sensations such as warmth or a feeling of speed and excitement were associated with enjoyment and contributed to the child's motivation to participate.

Adaptations to activities based on the child's needs, and an accessible and supportive environment fostered the children's positive experiences and attitudes towards participation. The findings emphasize the need to identify the personal and environmental factors that contribute to participation from the child's perspective. In adopting the children's viewpoints in this study, it was possible to recognize how children influence, choose and adapt their participation in activities, and also to identify factors that support and restrict participation. Some of the factors the children described were surprising, but nonetheless relevant, such as loud noises, cold and smells. These environmental factors limited the children's participation opportunities and motivation and might easily be overlooked in rehabilitation planning. Novel rehabilitation approaches recommend more emphasis being placed on the environment and how it can be changed in order to enhance children's participation (Anaby et al., 2014).

Three of the main elements that related to the children's meaningful participation in this study – autonomy, social involvement and capability – resemble the determinants of self-determination that, according to Ryan and Deci (2000), include autonomy, relatedness and competence. The same elements –experiencing fun, succeeding, belonging and freedom of opportunity to make choices – emerged as significant in a review by Willis et al. (2017) for children's and young people's participation experiences, and also in a review by Powrie et al. (2015) about the meaning of leisure activities. The results suggest that meaningful participation enables self-determination and enjoyment, and that promoting these elements in the activity context may increase the attractiveness of the activity and the child's motivation for participation.

Rehabilitation planning has long been based on the diagnosis, impairments and activity limitations, but increasing value is also being placed on the individual strengths, resources and preferences in the everyday lives of the child and family. The shift from the traditional biomechanical views of rehabilitation and "fixing" the child has progressed to underlining the "F-words" – family, function, fitness, fun, friends and the future – as presented by Rosenbaum and Gorter (2011). This study's results support this change – the same elements of fun, family and friends that are regarded as important by other children, with or without disabilities, were raised by every child in this study. The children described minor challenges or difficulties in their functioning, but focused more on what they could do, as pointed out by Schiariti et al. (2014). Further, the children actively made choices about how and when they would use their functional abilities. Consequently, rehabilitation

needs to progress from merely objective measuring of functional levels, impairments and needs to the identification of strengths, opportunities and individual preferences, supporting the agency of the child and family and co-creating solutions together in order to facilitate meaningful participation for the child in a real-life context.

This study's qualitative research design enabled the children's own perspectives to be the focus of attention without any expectations or limitations on the part of the researchers, as is the case with questionnaires, measures or more strict research designs. The photo-elicitation interviews served as a child-friendly means of understanding each child's perspectives. The photographs helped the researcher to ask and children to concretize different viewpoints from the real-life participation context. The older children and those without speech difficulties were able to articulate their thoughts vividly, while the younger children expressed themselves more through action, for example by showing how they could ride a bicycle and by indicating meaningful aspects of it. One key factor in capturing the children's views was that they prepared for the interview by taking pictures and that the interviews took place mostly in their own daily environment. At the end of the data analysis the study's main elements remained the same and no new categories emerged. The researcher was experienced in working with and interviewing children with disabilities; flexibility, playfulness and sensitivity toward the child's emotions, expressions and initiatives supported the children in expressing themselves and in minimizing the disparity of power between the adult interviewer and the child.

### **Implications for practice**

The elements contributing to meaningful participation from the child's perspective – enjoyment, social involvement, autonomy and capability – can be utilized in rehabilitation to facilitate interventions that the child is engaged with. The findings in this study support the use of participation-based approaches and emphasize the need to enable child's active agency in the collaborative rehabilitation planning. Promoting supporting elements and solving barriers in the activity context in order to achieve the child's participation goal is highlighted also in tools such as The Ecological Assessment of Activity and Participation (Palisano et al., 2012) and Pathways and Resources for Engagement and Participation (PREP) (Anaby et al., 2018).

The photo-elicitation interviews had the potential to act as a tool for identifying and exploring children's views about participation in a real-life context. When used as a complementary means in the interview process the photos enhance the credibility and consistency of the interpretation of child's opinion. The child's emotional, physical and information needs regarding the rules and expectations related to the participation context, and the necessary adaptations to the activity and the environment from the child's perspective should be addressed in order to facilitate participation. By exploring the aspirations, abilities, emotions, possibilities, dilemmas and choices children consider in relation to participation, and by identifying challenges and opportunities for the child to participate as an active agent in daily life and within rehabilitation practices, professionals are better able to co-create and fine-tune solutions for meaningful participation into the life of the child in collaboration with the family.

### **Limitations and further research**

The children in this study were able to make themselves understood, and hence there was a lack of participants who need more support to communicate. The study revealed some examples of the participation types children consider important and it is possible that the children emphasized leisure activities because the photographs were taken together with their parents and not while at school or daycare. Requesting the families to take photographs for a longer period, or in different situations and at different times, might have made the activities more varied. Children express themselves in many ways other than through words, and therefore something that the children were not able to articulate may have been discarded during the text analysis. We did not have an opportunity to triangulate nor perform member checking of the transcripts or themes. However, the main results of the study were discussed and reflected with three children (aged 7, 8 and 10 years) who did not belong to the study group and two external researches.

Further research is recommended on how supporters of and barriers to participation are viewed from the perspectives of professionals and parents, and on how to resolve participation barriers in order to enable the child's meaningful participation. Also, research on understanding the meaningful participation for adolescents is endorsed.



## CONCLUSIONS

Based on the results of this study, children value free leisure activities that foster enjoyment and support the realization of the child's self-determination by enabling social involvement with family and friends, facilitating experiences of capability, and providing the children with opportunities to exert an influence. The children's valuable insights into elements contributing to meaningful participation should be acknowledged, identified and adapted individually within rehabilitation practice in order to facilitate the child's participation in everyday life.

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